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Client Volunteering in Organizations Serving Individuals with Psychiatric Disabilities

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Introduction¹

The impetus for this research comes from a serendipitous but intriguing observation from a recent project of the Centre for Voluntary Sector Studies (CVSS). From 2001-2004, CVSS carried out a longitudinal evaluation of the impact of a new volunteer program on the well-being and activities of individuals with psychiatric disabilities residing in a supportive housing project. While all clients self-reported that they were happy to have volunteers working with them, observed findings indicated that there were very few behavioural improvements. However, one group of resident-clients defied this finding; they demonstrated marked behavioural improvements and their satisfaction levels were higher. Intrigued, we sought answers to these observations. It turned out that these individuals were not only beneficiaries of activities led by outside volunteers; they were also volunteering within their centre, supporting or facilitating activities for other client residents. Providing opportunities for clients with psychiatric disabilities to volunteer was an innovative development at this supportive housing centre, and the results were striking.

The purpose of the research reported in this paper was to survey organizations serving individuals with psychiatric disabilities in order to learn more about volunteering programs for individuals associated with or who are clients of these organizations. In this paper, we present results of our examination of volunteer programs in ten organizations serving people with psychiatric disabilities. We describe the nature of these programs, identify best practices and discuss the challenges and benefits they present. We begin the paper with a historical overview of mental health practices in Canada and then examine the rationale behind client volunteering. This is followed by a description of the methods used in this study, a presentation and discussion of our findings, and finally, some concluding observations including a summary of best practices.

Historical Context

Hundreds of thousands of Canadians face some form of mental or psychiatric disability in any given year (Health Canada, 2001).² The Participation and Activity Limitation Survey (PALS), a Canadian national survey on individuals with a disability, asserts that “more than half a million persons aged 15 and over (2.2% of the Canadian population) reported having activity limitations due to emotional, psychological or psychiatric conditions” (Statistics Canada, 2002, p. 17). These numbers are often surprising because mental illness continues to remain well hidden – a legacy of the stigma that has been historically attached to it. From the middle ages until the 20th century, individuals with a psychiatric disability were blamed for their condition, and were incarcerated in asylums and later on in special hospitals and institutions, isolated from

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² For the purpose of this paper, the terms psychiatric disability, client, consumer, survivor, volunteer and participant are used interchangeably, reflecting the diversity of terms used in the interviews we conducted. In the literature, there is much debate over definitions and terminology such as mental versus psychiatric and impairment, illness or disability. Some people who have experienced the mental health system self-define as a ‘consumer’ or ‘survivor’.

society. Hospitalization or institutionalization, accompanied by psychiatric therapies, such as lobotomy, electroshock therapy, and cocktails of tranquilizers, were the main forms of “treatments” for psychiatric patients until the late 1960s. These often experimental practices were criticized by the anti-psychiatry movement and by ‘consumer-survivors’ as abusive and degrading (Shimrat, 1997).

In recent decades, the mental health system has moved through a significant paradigm shift in the treatment of psychiatric disorders. A combination of medication treatment and community-based solutions, such as rehabilitation programs and supportive housing, shifted the focus of care from hospitals and institutions to the community in a process identified as deinstitutionalization. (Roehrer Institute, 1990, 1999; Sealy & Whitehead, 2004; Stroman, 2003). The deinstitutionalization process in Canada has been ongoing since the late 1960s, however, policies of deinstitutionalization have not been implemented consistently over the past 40 years; they have varied greatly across Canada both in practice and in the timing of the implementation. (Sealy and Whitehead, 2004). Even before deinstitutionalization became a policy, it was slowly becoming recognized that some kind of community-based services and supports had to be provided for people discharged from provincial mental health institutions.

Simmons (1990) notes that until the 1930s there were no organized “after care” programmes in Canada; it was not until 1945 that most provincial hospitals set up such programs. However, with their limited resources, they were unable to provide truly effective supports. Furthermore, in most cases, “community care” did not necessarily mean that people were reintegrated into the community; instead, local hospitals set up psychiatric units or day programs. In Ontario in the late 1970s to the mid-1980s, mainly in response to demands by newly established ex-patient groups, legislative changes were passed to address the rights of people with psychiatric disabilities. As Simmons (1990) contends, “During this period there was a clear trend in the direction of restricting psychiatric authority and extending patients’ rights” (p. 228).

In the past twenty years, Ontario has published four progressive mental health policy statements (in the years 1988, 1993, 1999, and 2002). Each policy document has taken an incremental approach to shifting the mental health system paradigm from an institutional system to a community-focused system that promises consumers a home, a job and a friend as well as access to treatment services as close to home as possible” (Lurie, 2004, p. 1). The Graham Report, released in 1988, was the first time that consumer/survivors were given a voice in policy making through community consultations (Ontario Ministry of Health, 1988). In 1991, the first patient advocacy program was established in Ontario. Since then, many community based non-profit organizations have been created both to address patients’ rights and to fill the gap in community-based services.

Following a US model, mental health agencies in Ontario established Assertive Community Treatment (ACT) teams as a way to offer less expensive community-based services. In this model, services such as case management, initial and ongoing assessments, employment and housing assistance, family support, and education are provided by a team of professionals available in the community 24-hours a day. Studies on the effectiveness of the ACT teams usually find that the number and duration of hospital stays and symptoms are reduced (Nelson,

Lord & Ochocka, 2001). Such success notwithstanding, ACT has garnered some criticism as well. Consumer-survivors cite concerns about the medical philosophy of ACT, claiming that there is too much social control, and insufficient emphasis on community involvement and informal supports.

Although deinstitutionalization was an important step in changing a system based on segregation, it was not without problems and controversies. People with severe mental illness are over-represented in the homeless population (Knowles, 2000) and in the criminal justice system. For example, in Toronto, an increased prevalence of mental illness among the homeless population over the past 30 years coincides with the closure of institutions for people with psychiatric disabilities (CPA, 1999). Some criticized the reasons and intentions behind deinstitutionalization as merely a fiscal move to cut government costs; others saw the greedy hand of the pharmaceutical industry influencing the new paradigm shift to rely more on medication (Simmons, 1990). Today, people with psychiatric disabilities continue to experience institutional and social discrimination and oppression, regardless of government and community-based initiatives. This is reflected by the fact that the employment of people with disabilities remains low, despite the policy and program initiatives designed to eradicate such problems (Crawford, 2004).

On the grassroots level, the mobilization of people with a psychiatric disability led to the establishment of various community-based supports, such as the Queen Street Outreach Society, a non-profit organization made up of consumer-survivors who offer outreach and education about mental health. Another interesting initiative in Ontario is the Ontario Council of Alternative Businesses (OCAB), a provincial survivor-run organization receiving funding from the Ministry of Health to provide employment opportunities for psychiatric consumer-survivors. Several such businesses operate in the Toronto area.

Many grassroots survivor-run self-help groups and advocacy-based groups exist in Canada (Shimrat, 1997). Consumer-survivor initiatives operate on peer support and self-determination principals, acting as an alternative to other services models (Nelson et al., 2006). Other community-based supports include employment-training programs such as “Clubhouses” where consumer-survivors are called members, and partake in unpaid tasks that are seen as essential to running the organization (Macias, Kinney, & Rodican, 1995). Chipperfield and Aubrey (1990) discuss the Supportive Housing Program model, which is based on a consumer-directed model of service provision where rehabilitation principles facilitate opportunities for skills development (Besio & Mahler, 1993).

Community-based and community-oriented programs such as those described above are on the rise in Canada. Some programs and business initiatives are run by psychiatric consumers-survivors (Mowbray et al, 1996) while others are supported and promoted through government initiatives with the intention of integrating people with psychiatric disabilities into the community. Findings of a recent study by the Canadian Mental Health Evaluation Initiative show that “community mental health is making a difference in the lives of people with serious mental illness, their families, and caregivers” (Goering, 2004, p. 43). Clients experienced an improvement in their daily living and a reduction in symptoms and substance abuse; they were also subject to fewer crisis episodes and spent far fewer days in hospital (Goering, 2004).

However, among all these initiatives, little research attention has focused on programs providing clients with psychiatric disabilities opportunities to volunteer.

Client Volunteering

Client-volunteering programs in mental health services are a relatively new development in integrating people with psychiatric disabilities into society (Cook & Picket, 1994; Firth & Kerfoot, 1997; Weaver, 1993). In the late 1980s, a significant increase was recorded in the number of people with psychiatric disabilities referred to volunteer work through volunteer centres and employment agencies (CVBOC, 1988). This was interpreted to be a reflection of “a general shift in the treatment of those experiencing mental health problems, including deinstitutionalization and development of community-based programs” (CVBOC, 1988, p. 38). However, since then, few Canadian research studies have focused on actual volunteering experiences of people with psychiatric disabilities.

Indeed, the numerous manuals outlining strategies and techniques for the recruitment, training and retention of volunteers are largely silent on the subject of volunteering among individuals with psychiatric disabilities, even while acknowledging the challenges facing people with other disabilities (Itzhaky & Schwartz, 1998; VDS, 2005). Itzhaky and Schwartz (1998) found that individuals with disabilities volunteering in organizations for people with disabilities were able to empower both themselves (e.g., improved self-esteem) and the organization (e.g., representation and participation of the disabled in decision-making). A recent provincial report on human resources in the health care system noted that a number of mental health and addiction programs, faced with shortages of trained health professionals, use former clients, and in some cases client volunteers who work under the supervision of staff, to assist with outreach, run peer-led programs, or act as case managers (ODHC, 2003).

The sporadic studies published in Canada about opportunities for, and barriers to, volunteer participation among people with disabilities can be divided into three broad categories:

1. Studies identifying barriers to volunteering, suggesting how barriers can be reduced, and describing how to engage people with disabilities as volunteers (Schmidl, 2005; Volunteer Canada, 2001; Pyle, 1997);
2. Studies focusing on supported volunteer programs, the challenges they face, and factors in their success (Graff, 1992, 1998; Lautenschlager, 1992);
3. Studies concentrating specifically on issues facing people with psychiatric disabilities (MacKinnon, 1991; CVBOC, 1988).

The latter studies date back more than a decade, again suggesting that research on volunteering among people with psychiatric disabilities has been overlooked in recent years.

Methods

In order to address the lack of research on volunteering among people with psychiatric disabilities, we studied ten volunteering programs in the Greater Toronto Area. In this paper, we are describing the first stage of a two-stage project - surveying volunteering programs in organizations providing services to people with psychiatric disabilities. The second stage will evaluate the impact of volunteering on the well-being and integration of people with psychiatric

disabilities into community. The research reported here is based on key informant in-depth interviews with volunteer coordinators or program directors of organizations providing services to people with psychiatric disabilities.

Sample

In order to attain a sample of organizations providing volunteering opportunities to people with psychiatric disabilities, we first created a list of organizations serving this population in the Greater Toronto area. We contacted organizations on the list, selected at random, and asked them some screening questions pertaining to client volunteering. We then arranged on-site interviews with key informants (volunteer coordinators or program directors) of organizations that passed our screening criteria and agreed to participate. We expanded the diversity of organizations using a snowball sampling method, in which a randomly chosen sample serves as initial contacts and these initial contacts provide the names of other organizations that might match the research criteria (Goodman, 1961). Despite criticism of this non-probability sampling (Erickson, 1979), this sampling method suffices for the pilot nature of this current phase. The resulting sample of ten consisted of a mix of organizations from the list, and organizations recommended by our interviewees. In all, six different types of organizations were in the sample; they are listed below and are referred to in the findings using the following acronyms to allow anonymity:

- 2 Drop-in centres (DI)
- 2 Job placement centres (JP)
- 1 Educational institution (EI)
- 3 Supportive housing organizations (SH)
- 1 Medical/clinical centre (MC)
- 1 Mixed function: Day rehabilitation, supportive housing and assertive community training. (MF)

Interviews

Semi-structured in-depth interviews of about one hour in length were conducted with key informants. At three of the interviews, more than one organizational representative was present. We followed a similar interview protocol for all organizations. We started the interviews by asking the respondents to “tell us a little bit about your organization” including mandate, age, types of clients, budget, and number of employees. We then asked them to tell us about their client-volunteering program using a checklist of items we wanted covered. If items on the checklist were not mentioned, we prompted them with specific questions. The information sought included:

- When and how the client-volunteering program started
- Whether the program was formal or ad hoc
- Participation and nature of the program (number of participants; requirements; how do they choose activities; what activities do they do; where do they volunteer; support for learning; nature of volunteering: episodic, project related or regularly scheduled; does it lead to a job?)

- Administrative aspects of the program (Who is in charge? How many people are involved? What is the role of the board? Are client-volunteers on the board?)
- Supervision (Who? How? Where? including availability of training for supervisors, training for volunteers, difficulties in supervising, and prescription for success)
- Difficulties in setting up and running the program (crisis management, volunteer relapses, barriers to participation);
- Funding dedicated to the program;

We concluded the interview by asking them to summarize their general impressions of their program: Is it successful? How might it be improved? What are the benefits to the volunteers, the organizations, society?

All of the interviews were digitally recorded and notes were taken manually by interviewers. This paper presents a preliminary analysis of the notes, transcripts and interview recordings. From our review of the tapes and transcripts, we identified both prescribed and emergent themes. Subsequent analysis of the transcripts will involve further content analysis and coding according to both prescribed and emergent themes, and the three main program objectives that emerged in our preliminary analysis.

Findings

It became clear when analysing the interviews that the organizations studied differ significantly in their objectives with respect to their volunteer programs. We identified three types of overtly stated objectives:

- (1) programs which see volunteering as a stepping-stone to employment (EI, JP-1, JP-1);
- (2) programs that see volunteering as a means of rehabilitation and a part of personal recovery of clients (DI-1, MI, SH-1 and SH-3); and,
- (3) programs that see volunteering as participation and integration in community (CM, DI-1, DI-1, SH-1, SH-2, SH-3).

We also discerned another objective, one that was not explicitly enunciated, but often alluded to: using volunteers for the benefit of the organization. Half of the organizations in our sample fit into this category (CM, DI-1, DI-2, SH-1). This is not surprising, given funding cuts and shortages of trained professionals at these organizations (ODHC, 2003)..

Table 1. Summary of Results

Main Objectives	Volunteering as a stepping stone to employment	Volunteering as rehabilitation and part of personal recovery	Volunteering as community participation
Organizations	EI, JP-1, JP-2	DI-1, MF, SH-1, SH-3	CM, DI-1, DI-2, SH-1, SH-2, SH-3,
Reasons clients volunteer (as reported by respondents)	Job skills development	Life skills development	Social integration; Affiliation with program members; To “give back to the community”

Volunteer placement	External	Internal	Internal
Remuneration	Some money from ODSP for transportation costs	Some honoraria at MF and SH-1	Some honoraria at SH-1 and DI-2
Volunteer recognition	No	DI-1 and SH-3	DI-2
Barriers to volunteering	<p>External</p> <ol style="list-style-type: none"> 1. Increased competition for volunteer positions 2. Stigma of mental illness <p>Internal</p> <ol style="list-style-type: none"> 3. “Stigma of volunteering” 4. Fear of responsibility 5. Fear that supervision might be inadequate 6. Fear of not knowing anyone 7. Side-effects of medication 8. Lack of self-confidence 	<p>External</p> <ol style="list-style-type: none"> 1. Inability to depend on volunteer 2. Unwilling/unable to provide support volunteers need 3. Unable to provide needed flexibility 4. Stigma of mental illness <p>Internal</p> <ol style="list-style-type: none"> 3. Lack of confidence 4. Anxiety 5. Need time to deal with impairment 6. Limited skills 7. Not wanting to socialize 8. Other commitments (e.g. paid work) 	<p>External</p> <ol style="list-style-type: none"> 1. Discrimination, stigma of mental illness 2. Lack of funding to help place clients <p>Internal</p> <ol style="list-style-type: none"> 3. Unable to get necessary information 4. No contacts 5. Get lost in the shuffle 6. Lack of confidence 7. Lack of work skills, social skills and life skills
Benefits of volunteering	<p>Builds confidence, self-esteem, stamina, sense of responsibility and work tolerance</p> <p>Helps personal and social development, gives people an identity beyond that associated with their mental health</p> <p>Allows volunteer to experiment with different places and find best fit</p> <p>Volunteer placements show more understanding of clients’ limitations than employers for pay may</p>	<p>Helps regain lost skills, therapeutic effect</p> <p>Opportunities for social interaction and peer support</p>	<p>Allows extra benefits through OW or ODSP</p> <p>Gives hope, fulfillment, confidence, sense of responsibility, feeling of being needed/ listened to</p> <p>Provides training, skill development, social skills, the experience of “fitting in” and a social outlet</p> <p>Gives pride/ reciprocity in giving back to community</p> <p>Helps identify limitations and means to</p>

			deal with medication side effects Reduces medical incidents Develop intrinsic motivation for further volunteering
Formal vs. informal programs	Formal	Informal (SH-1, MF) Formal (SH-3) Informal & Formal aspects (DI-1)	Formal (SH-3) Informal (SH-2)
Program for clients or both clients and general public	Only clients	Only clients (SH-1, DI-1, MF) Integrated (SH-3)	Integrated (DI-2, SH-3 CM) Clients only (SH-2)

We reviewed the themes that emerged from our interviews and organized them according to the three types of overt program objectives. Table 1 summarizes these findings. The major differences we found were between the organizations that saw volunteering as a stepping-stone to employment on the one hand, and those that saw volunteering as a part of personal recovery or community participation, on the other hand. “Stepping-stone” organizations viewed volunteering as a step in the client’s progress towards achieving regular employment in the broader community, whereas for the other organizations, the experience of volunteering was seen as an end in itself, for the benefit of the individual or the community. Furthermore, although volunteering opportunities were encouraged wherever they were to be found, it was only among the “stepping-stone” organizations that external placements were the norm. The other organizations concentrated on providing volunteer opportunities within their own organization. In fact, one of the respondents pointed out that her organization provides internal volunteering opportunities because of the great difficulty consumer-survivors have finding contacts and information about volunteer placements “on the outside”.

Because of their external orientation, the stepping-stone organizations report different kinds of barriers in relation to volunteering. While all organizations see the “stigma of mental illness” as a key barrier, only stepping stone organizations referred to a competitive climate in getting volunteer placements within the few organizations that open their doors to volunteers with psychiatric disabilities. It is, however, with respect to internal barriers that the difference between the groups is most apparent. Whereas all of the key informants mentioned different kinds of fears, limitations in skill sets, and lack of confidence or medication/illness related barriers, only the stepping stone organizations mentioned a phenomenon that one respondent coined “the stigma of volunteering”. Our respondents reported that some consumer survivors refuse to volunteer because they see it as a stigma; it classifies them as being unable to get paid work. Other informants suggested that volunteer labour might be seen as exploitation, and that this perception could also be a barrier to participation.

With respect to benefits, the differences are not substantial. Respondents see volunteering as helping their clients improve skills – life skills, social skills and vocational skills, and increase their self-esteem. Volunteering also gives clients hope, pride and the feeling of being needed. It provides them with socialization opportunities and the “experience of fitting in”. One respondent remarked that he noticed a reduction of medical incidents among volunteers (CM). Stepping stone organizations are the only ones to refer to the benefits of volunteering in terms of preparing their clients for jobs, allowing them to experiment with different workplaces to make them “work-ready” and helping to ease them into a job. They also acknowledged that voluntary organizations are more understanding of, and more inclined to overlook the volunteers’ limitations.

The organizations whose programs were oriented to recovery or community participation share many similarities. A key difference between these two types is in their approach to recovery. In the rehabilitation-type programs the focus is on a volunteer’s individual skill development and recovery needs. Community oriented programs, however, focus on the integration of consumers in the fabric of society at large, both as a means for individual consumers to develop their skills and their social network, and as a means for community development and mainstreaming mental health concerns in society. Thus, whereas rehabilitation programs focus on skill development at an individual level, community programs put skill development in the context of a social group.

Best Practices

Across the interviews, a number of best practices in client volunteer programming emerged. The foremost concern expressed by informants was that a program should be flexible enough to accommodate an individual volunteer’s needs, which are subject to change, and adaptable in how a volunteer participates in a program. For example, on short notice a volunteer might need to change tasks to accommodate the side-effects of a medication. Respondents added that flexible practice was best balanced with clearly defined roles and program structure. The volunteer roles assigned should be realistic and based on a volunteer’s skill sets. Respondents mentioned that, as in any position, the provision of sufficient training and support is important for a successful volunteer placement. Further, it was generally agreed that program participants should be offered clear instruction and feedback, and recognition for their contribution. Interviewees expressed a preference for program administration focusing on the needs of the individual volunteer and involving consumers at all levels, including assigning roles. Finally, respondents also felt that a program should aim to create a safe environment for consumers to take risks in developing skills and relationships. Illustrating this need, representatives from community oriented programs asserted that a safe space facilitates the establishment and normalizing of acceptable social boundaries for volunteers.

Discussion and conclusions

In our western culture, we value volunteering and community participation as the cornerstone of our democracies, promoting citizenship and inclusiveness while building and maintaining civil society. Studies looking at volunteering among physically and intellectually disabled individuals attest to the sense of inclusion and increased self-esteem experienced by the volunteers. These volunteering opportunities are arranged mostly through organizations already providing support to people with disabilities, however volunteer centres and other voluntary organizations have been making progress in reducing barriers and providing increased opportunities for people with physical disabilities. People with psychiatric disabilities form a largely hidden population and their volunteering activities have not been the subject of recent research.

Our research indicates that there are several programs providing volunteer opportunities for people with psychiatric disabilities. In our sample, volunteering is encouraged and supported by several types of organizations: educational institutions, job placement organizations, supportive housing agencies, clinics, rehabilitation centres and drop-in centres. In some of these organizations, volunteering is part of a formal program, whereas in others it is more informal but definitely encouraged and supported. Some organizations provide only in-house opportunities to volunteer, while others encourage, support or arrange volunteering with outside agencies.

From our analysis of the interviews, we realized that organizations have different objectives with respect to their volunteer programs. The educational institute and job placement agencies in our sample were inclined to use volunteering as a stepping-stone towards attaining paid employment, whereas the rest of the organizations encouraged and supported volunteering either as part of rehabilitation and personal recovery, or as community and social integration. Some organizations did both.

The stepping-stone programs focus on finding appropriate placements for the individual in order to prepare him/her for a job. Recovery oriented programs use recovery checklists developed by clients in partnership with their caseworkers, thereby involving volunteers in directing their own recovery process. Community oriented programs view individual social benefits of volunteering in relation to the larger community.

Although volunteering is generally viewed in a positive manner, this is not always true for people with disabilities. In fact, for some people there is a stigma associated with volunteering. People with disabilities typically experience significant barriers to obtaining paid employment. This persists, even though in recent years a number of training and employment initiatives have been instituted to support people with disabilities in obtaining and keeping paid jobs. According to the Canadian Council on Social Development, in the year 2000, 46.7% of women and 36.5% of men with disabilities were not gainfully employed. This stands in stark contrast to the general, non-disabled population, where only 22.5% of non-disabled women and 12.8% of non-disabled men were unemployed. Thus, three times as many disabled men and twice as many disabled women were out of work than their non-disabled peers. For disabled people who want to work, having to resort to volunteering can indeed be perceived as a stigma.

Employment programs too, pose problems. Many operate on a “readiness” model, where people with disabilities have to demonstrate their skills in order to get into a program and receive employment supports. The social service provider decides when someone is “able” to work, so when a disabled person is deemed to be “not employable”, they are forced into volunteering. For a non-disabled people, having the opportunity to volunteer is a real choice; for the disabled it is often a forced choice because jobs are not available, or because it is a condition for receiving social supports.

These issues notwithstanding, our respondents identified several important benefits of volunteering related to developing life, job and social skills, as well as increasing self confidence and providing a sense of well-being and fitting in. Although external barriers were mentioned, with the stigma of mental illness being in the forefront, most of the barriers were seen by our respondents to be internal ones, related to lack of confidence and self-esteem, which the volunteer programs were designed to overcome.

In the next phase of our study, we will be interviewing client-volunteers to learn directly from them how they feel about their volunteering experiences.

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